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Supreme Court of the United States

October Term, 1989

LOUIS SULLIVAN, Secretary of Health and Human Services, Petitioner,

E.

Brian Zebley, et al., Respondents.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE THIRD CIRCUIT

BRIEF AMICI CURIAE OF THE MEDICAL ISSUES TASK FORCE OF THE UNITED HANDICAPPED FEDERATION AND THE ETHICS AND ADVOCACY TASK FORCE OF THE NURSING HOME ACTION GROUP IN SUPPORT OF RESPONDENTS BRIAN ZEBLEY, ET AL.

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INTEREST OF AMICI

The United Handicapped Federation (UHF) is a non-profit corporation founded in 1974. UHF is headquartered in Minnesota and has approximately 15,000 members in a number of states; it represents a disability rights coalition of 51 organizations. The general membership of UHF is composed of persons

with disabilities, their parents, friends and relatives, concerned professionals and other interested persons. UHF pursues four goals on behalf of persons with disabilities: 1) to ensure their access to decision-making processes affecting their lives and concerns; 2) to promote their rights and responsibilities; 3) to assist their efforts to live independently and to participate fully in the community; and 4) to educate temporarily-abled people about the needs, concerns and image of persons with disabilities. A substantial portion of the UHF membership is indigent and receives public assistance, including Supplemental Security Income (SSI) and Medicaid. The UHF Medical Issues Task Force has participated as amicus curiae in several court cases involving threats to the provision of treatment and care for persons with disabilities. These cases have included children needing medical treatment. UHF and its Medical Issues Task Force are concerned about the impact the Secretary's child disability policies will have on the quality and availability of medical care for children with disabilities.

The Ethics and Advocacy Task Force of the Nursing Home Action Group advocates needed medical care and treatment for residents of nursing homes and long-term care facilities. Such persons, adults and children alike, are vulnerable to discrimination based on disability, illness, age or unjust economic priorities. The Task Force is a committee of the Nursing Home Action Group, a non-profit corporation with membership throughout the United States. Founded in 1983, the Nursing Home Action Group promotes the rights and interests of nursing home and long-term care facility residents, including a reported total of 100,000 children nationally, through legislation, advocacy, counseling, and networking. The majority of its membership consists of indigent persons with permanent physical or mental disabilities.

The UHF Medical Issues Task Force and the Ethics and Advocacy Task Force of the Nursing Home Action Group are represented by attorneys of the National Legal Center for the Medically Dependent and Disabled, a national support center of the Legal Services Corporation The National Legal Center for the Medically Dependent and Disabled serves indigent persons whose lives are jeopardized by denial of medical treatment or care on account of disability.

All parties have consented in writing to the filing of this brief.

SUMMARY OF ARGUMENT

The standards employed by the Social Security Administration to determine eligibility for Supplemental Security Income (SSI) and defended by the Secretary of Health and Human Services (hereinafter "the Secretary") treats children differently than adults. This different treatment raises equal protection and due process concerns; it also affects a large population of similarly vulnerable children by increasing the risk of discriminatory denial of medical services.

ARGUMENT

 To Avoid Constitutional Concerns, The SSI Regulatory Scheme For Children Should Be Held Inconsistent With Congressional Intent.

Congress established the SSI program in 1972 to provide federal assistance to needy disabled, blind, and aged persons under Title XVI of the Social Security Act. 42 U.S.C. 1381-1383c (Supp. 1989). Pursuant to congressional direction, the Secretary has promulgated regulations to administer the SSI program. See 20 C.F.R. §§416.101—416.2119, Subpts. A-U (1987). At issue in this case are the regulatory standards (hereinafter "the Regulations" or "the regulatory scheme") that the Secretary created to determine SSI eligibility by measuring an applicant's level of mental or physical impairment. See 20 C.F.R. 416.920 (1987) and 20 C.F.R. 416.924 (1987).

Your amici agree with Respondents Brian Zebley, Joseph Love, Jr. and Evelyn Raushi that "the Secretary has established two markedly different regulatory tests to measure the disabling severity of the impairments of adult and child claimants. This very disparate treatment is at the heart of this case." Respondents' Brief in Opposition to Petition for a Writ of Certiorari to the United States Court of Appeals for the Third Circuit at 5.

The issue debated by the Secretary and the Respondents is not whether the Regulations treat children differently than adults. Quite clearly they do, and the Secretary admits this, though grudgingly. Petition for a Writ of Certiorari to the United States Court of Appeals for the Third Circuit at 4 ("Children are evaluated on a slightly offerent standard.") Rather, the parties dispute whether the Regulations, in treating children differently than adults, are consistent with the mandate of Congress. Do the Regulations properly implement the intent of Congress as expressed in 42 U.S.C. 1382c(a)(3)(A) (Supp. 1989)? What did Congress intend when it directed the Secretary not only to assist adults with severe impairments, but also to help children with impairments of "comparable severity?" The Secretary asserts one meaning of the crucial words "comparable severity" and the Responde as another.

When a statute may be interpreted in two or more ways, that interpretation "clearly in accordance with the provisions of the constitution is to be preferred." Knight Templars' & Masons' Life Indemnity Co. v. Jarman, 187 U.S. 197, 205 (1902). This

long recognized rule "plainly must mean that where a statute is susceptible of two constructions, by one of which grave and doubtful constitutional questions arise and by the other of which such questions are avoided, [the Court's] duty is to adopt the latter." United States ex rel. Attorney Gen. v. Del. & Hudson Co., 213 U.S. 366, 408 (1909). "This cardinal principle . . . has for so long been applied by this Court that it is beyond debate." Edward J. DeBartolo Corp. v. Fla. Gulf Coast Bldg. & Construction Trades Council, 108 S. Ct. 1392, 1397 (1988).

Your amici assert the SSI regulatory scheme, based on the Secretary's interpretation of the SSI statute, raises "grave and doubtful constitutional questions." If the Regulations are deemed consistent with the federal law authorizing the SSI program, then that law's constitutional validity is also suspect.

What are the Regulations' constitutional problems? The Regulations violate the rights of children with disabilities to equal treatment and due process of law.

A. The SSI Regulations Fail To Provide Equal Protection.

Your amici assert that the SSI Regulations fail to provide equal protection because they disfavor children, conflict with an important purpose of the SSI program and are unsupported by any rational basis.

The SSI Regulations discriminate against children with disabilities.

At one stage of the SSI eligibility process, both adults and children must attempt to prove that their physical or mental impairment matches an impairment defined and listed by the Secretary in a listing of impairments (hereinafter "the Listings") published in the Regulations. See 20 C.F.R. Pt. 404 Subpt. P, Apps. 1-2 (1987). The crucial and constitutionally defective difference between the Regulations' treatment of adults and their treatment of children occurs when a member of

The Regulations cut in two directions. They differentiate between adults and children, a "vertical" distinction. They also differentiate between medically impaired children with conditions meeting the Listing of Impairments and those other medically impaired children whose conditions do not meet the Listings, a "horizontal" distinction. Your amici will focus in this section on the constitutional implications of a "vertical" distinction between adults and children. The "horizontal" impact is also problematic, however. By extending SSI eligibility only to those children impaired to such a severe level as to be presumed disabled, the Secretary withholds eligibility from those children having no one condition as severe as a listed one, but who might actually be disabled when the combined impact of all the child's functional deficits is considered. There is no rational basis for the Secretary to choose to help presumably disabled children but not help those actually disabled.

either group fails to demonstrate that his or her impairments meet or equal any one impairment included in the Listings.

The SSI regulatory scheme at this stage disfavors children by denying them the opportunity to go beyond the Listings to seek individualized assessments of their "residual functional capacity" (RFC). Social Security Administration, Program Operation Manual System, Disability Insurance, \$24505.015. As a result, unlike adults, children cannot demonstrate that the impairments they possess, considered separately or together, effectively disable them from doing "any substantial gainful activity." 20 C.F.R. \$416.924 (1987). Instead, children must depend solely on "meeting or equaling" the higher severity threshold found in the Listings. The Listings contain only those medical impairments presumed by the Secretary to be so severe as to prevent individuals from performing "any gainful activity." 20 C.F.R. \$416.925(a) (1987); 20 C.F.R. \$416.925 (1987).

Adults, on the other hand, may present to the Secretary evidence of any functional limitations caused by medical impairments. 20 C.F.R. §§416.960 — 969 (1987). Separately, each impairment might fail to "meet or equal" the high severity level of those found in the Listings. Together, the combined impairments may be found to prevent the adult from performing any substantial activity, a lower severity level. Thus, the opportunity to show the combined effect of several impairments on one's functional capacities is afforded only to adults under the Regulations.

If adults cannot meet the higher severity threshold found in the Listings, then they still may meet the lower threshold found at the RFC assessment stage. An individualized RFC determination permits adults to go beyond the Listings to prove they are disabled and therefore SSI-eligible. In effect, therefore, adults carry a lighter burden when applying for SSI benefits. These divergent regulatory schemes thus place before children obstacles to receiving SSI benefits greater than those encountered by adults. A disproportionately larger number of denials of SSI for children has thus resulted. See Appellants Reply Brief, Appeal from the United States District Court for the Eastern District of Pennsylvania at 2-3 ("The data further suggests that in contrast to the adult program many more severely disabled children apply, get beyond the "severe" mental or physical impairment stage [of evaluation], but get turned down not because of other reasons such as excess income or resources, short duration of impairment, or insufficient medical evidence, but largely because they do not 'meet or equal' the Listings standards.")

As your amici will show, this different treatment is wholly unrelated to, indeed contravenes, an important purpose of the SSI program. Hence, under equal protection analysis, the different treatment is "so attenuated" to the SSI program's goals as to be arbitrary and irrational.

 By discriminating against children with disabilities the SSI Regulations conflict with an essential purpose of the SSI program: providing access to healthcare financing under Medicaid for both adults and children.

The constitutional guarantee of equal protection "is essentially a direction that all persons similarly situated should be treated alike." City of Cleburne v. Cleburne Living Center, Inc. 473 U.S. 432, 439 (1985). Government action is invalid under equal protection analysis if it interferes with a fundamental right or discriminates against a suspect class. Kadrmas v. Dickinson Public School, 108 S. Ct. 2481, 2487 (1988). Cases involving governmental distinctions based on age, Massachusetts Board of Retirement v. Murgia, 427 U.S. 307, 313 (1976), or mental disability, Cleburne, 473 U.S. at 442, according to this Court, do not involve suspect or a quasi-suspect

classifications. In such cases, a rational basis test is applied: the classification drawn must rationally relate to a legitimate government interest. *Lyng v. International Union*, 108 S. Ct. 1184, 1191-92 (1988).

This test, though deferential, "is not a toothless one." Matthews v. Lucas, 427 U.S. 495, 510 (1976). "Arbitrary and irrational discrimination violates [equal protection guarantees in the Constitution] under even our most deferential standard of review." Bankers Life & Casualty Co. v. Crenshaw, 108 S. Ct. 1645, 1653 (1988). Thus, for example, the Secretary "may not rely on a classification whose relationship to an asserted goal is so attenuated as to render the distinction arbitrary or irrational." Cleburne, 473 U.S. at 446.

As acknowledged by the Secretary, Congress not only intended to provide income supplements under SSI, but also intended to broaden access to health care. See Brief for the Petitioner at 45. States are encouraged by Congress to automatically qualify SSI recipients for state Medicaid health coverage. 42 U.S.C. §1396a (a)(10)(A)(i) (Supp. 1989). (Forty-one states now extend automatic coverage under Medicaid to all disabled children and adults receiving SSI. Fox & Greaney, Disabled Children's Access to Supplemental Security Income and Medicaid Benefits 27 (Dec. 1988)). An irtended result of the SSI program is to place desperately needed health care financing within the reach of adults and children with disabilities.

The SSI program is not intended only to assist those persons whose disabilities prevent them from earning a living. This employment-oriented purpose co-exists with another: the purpose of providing access to health care. The latter purpose relates to adults and children equally. Both adults and children can benefit from and achieve rehabilitation through health services.

Thus, children and adults should be treated equally under SSI to further Congress' intent to avail health care to all persons with disabilities. The Secretary should not distinguish between adults and children on the basis of their functional capacities in determining whether or not to provide SSI. SSI eligibility decisions ultimately affect many applicants' chances of receiving Medicaid coverage, which in turn governs their ability to obtain needed health care. Denying RFC assessments from children while providing the same to adults treats similarly situated classes differently on the basis of an irrelevant distinction. This different treatment contravenes the Fifth Amendment's guarantee of equal protection.

The SSI Regulations are unsupported by any rational basis.

The Regulations will not survive even minimal equal protection scrutiny unless the Secretary included in the administrative record a rational basis for treating children differently than adults. Regulations can only be upheld, "if at all, on the basis articulated by the agency itself." Motor Vehicle Mfrs. Assn. v. State Farm Mut., 463 U.S. 29, 50 (1983). If no justification is provided at the time a federal regulation is promulgated. then this Court refuses to search for any "conceivable basis" to save the regulations from constitutional invalidation. "Agency deference has not come so far that we will uphold regulations whenever it is possible to 'conceive a basis' for administrative action. To the contrary, the 'presumption of regularity afforded an agency in fulfilling its statutory mandate,' is not equivalent to 'the minimum rationality a statute must bear in order to withstand analysis under the [Fifth Amendment's] Due Process Clause.'" Bowen v. American Hospital Assn., 476 U.S. 610, 626 (1986) 'citing State Farm Mut., 463 U.S., at 43 n.9). Any such regulation would therefore be unconstitutional because the agency failed to carry out its duty to explain the rationale and factual basis of its action. Id.

The administrative record created when the SSI Regulations were promulgated offers no clue why the Secretary believes functional evaluations, as opposed to vocational ones, are inappropriate for children. As noted by one federal district court that disapproved the child SSI regulatory scheme:

The Secretary does not attempt to grapple with the application of inconsistent statutory standards, nor does he address the inherent flaws in the cookbook adjudicatory format of his regulatory scheme. Instead, he repeatedly announces that the determination of a child's RFC would be inappropriate since the statute does not require application of the vocational factors to child SSI claims. This is a non sequiter. Determination of the child's functional capacities in light of his or her medical condition—a medical determination—operates separately from step five in the regulatory scheme, which applies a wage earner's vocational factors.

Marcus v. Bowen, 696 F. Supp. 364, 381 (N.D. Ill. 1988).

An after-the-fact justification will not save the Regulations if the justification finds no support in the administrative record. The mere fact there might be "some rational basis within the knowledge and experience of the regulators, under which they might have concluded that the regulation was necessary to discharge their statutorily-charged mission, will not suffice to validate agency decision-making." Bowen v. American Hospital Assn., 476 U.S. at 627. Even if the Secretary's last minute efforts to explain his actions (see Petitioner's Brief, at 41-46) provided this Court with a reasonable basis for the SSI policy (which your amici do not concede), the absence in the administrative record of any justification and corresponding evidentiary support is nonetheless constitutionally fatal.

Assuming for the sake of argument the Secretary had met his burden of articulating in the administrative record some basis for discriminating against disabled children, that basis itself is still susceptible to constitutional challenge. If the "facts on which the classification is apparently based could not reasonably be conceived to be true by the decisionmaker." then the classification will not survive equal protection scrutiny. New York State Club Assn., Inc. v. City of New York, 108 S. Ct. 2225, 2236 (1988) (quoting Vance v. Brudley, 440 U.S. 93, 111 (1979)). That is, a constitutional challenge will succeed if evidence is submitted "to show that the asserted grounds for the

. . . classification lack any reasonable support in fact." City of New York, 108 S. Ct. at 2236.

The Secretary has offered this Court several assertions he claims justify the SSI Regulations' different treatment of children and adults. Your amici argue that these assertions are "erroneous and that the issue is not truly debatable," see 108 S. Ct. at 2236, and that the Regulations therefore lack any rational basis.

The Secretary argues that children are not provided individualized assessments beyond the Listings because such assessments are concerned with work-related capacities. Because children generally do not have past work experience or seek employment, the Secretary argues it is rational to provide RFC evaluations for adults, but not for children.

Your amici disagree. According to the Regulations themselves, the individual assessments provided to adults consist of two different evaluations: functional and vocational. The functional RFC evaluation is defined as a "medical assessment" based on criteria not solely work-related 20 C.F.R. §416.925 (1987). RFC determinations measure such physical abilities as "walking, standing, lifting, carrying, pushing, pulling, reaching, [and] handling" (20 C.F.R. §8404, 1545(b), 416.945(b) (1987)), and such mental "factors . . . as [the] ability to understand [and] to carry out and remember instructions" (20 C.F.R. §8404.545(c), 416.945(c) (1987)).

The vocational assessments of age, education, and work experience are clearly distinguished in the Regulations from RFC determinations. See S. S. R. 83-10 (West Soc. Sec. Rep. Serv. Supp. 1988); Marcus v. Bowen, 696 F. Supp. at 381 ("Determination of the child's functional capacities in light of his or her medical condition — a medical determination — operates separately from step five in the regulatory scheme, which applies a wage earner's vocational factors".)

On the one hand, children are different from adults with respect to their present connection to the work force and their present employability. On the other hand, children as well as adults can be functionally impaired and thus functionally evaluated according to age-appropriate standards. For adults, functional impairments may hinde, or extinguish their ability to hold a job, an age-appropriate activity. For children, functional impairments may interfere with such age-appropriate tasks as school, social interaction, physical mobility, or other activities related to social and educational development. The impact on adult or child age-appropriate abilities is equally measurable through an RFC assessment. Thus, there is nothing so inherently "job-related" about an RFC assessment that should limit its applicability only to adults.

Because it is a functional and not solely job-related assessment, the RFC evaluation is equally applicable to children and adults. Therefore, children should not be denied the opportunity to receive individualized, medically determinable, functional evaluations.

The Secretary also asserts that employing functional assessments for children across the board would be unworkable. Brief for the Petitioner at 44. This assertion is unreasonable since the Secretary already provides children certain, though severely limited, opportunities within the Listings for individualized assessments patterned after those afforded adults. Thus, RFC-evaluations for children are not technologically or administratively impossible. In addition, the Secretary requires individualized functional and even vocational assessments of children in cases where children on SSI have to be reassessed when medical improvement may have occurred. (See 20 C.F.R. §416.994(c) (1987): An inquiry is needed into "whether this medical improvement is related to your ability to work (i.e., your ability to perform age-related activities.)")

The Secretary also asserts that the Listings for children are a sufficient substitute for across-the-board functional assessments. Brief for the Petitioner at 42. This also is an unreasonable assertion given the Secretary's own recognition of the Listings' incomplete scope.

Responding to a public comment submitted in 1978 that the Listings failed to include numerous disabling conditions, the Secretary concurred: "This is true. The Listing criteria are intended to identify the more commonly occurring impairments shown in applications for social security disability benefits." 44 Fed. Reg. 18175 (1979). Another comment argued that the Listings insufficiently described the symptoms of multiple sclerosis. Id. at 18176. The Secretary replied:

It is not possible . . . to reduce these multiple manifestations to a listing. The Listing is but one item in the evaluation process. We evaluate cases of claimants whose conditions do not meet or medically equal the criteria of a listed impairment under other rules. Under these rules we consider the person's condition, age, education, and work experience to determine whether the person is disabled.

Id.

The Third Circuit Court of Appeals echoed the Secretary on the Listings' incompleteness by noting "numerous examples alleged by amici... demonstrate the inadequacy of the Secretary's exclusive reliance [in children's cases] on the medical listings." Zebiey v. Bowen, 855 F.2d 67, 72 (3rd Cir. 1988). The Third Circuit thus ruled that children should be provided individualized assessments because,

[t]he listings . . . do not purport to be an exhaustive compilation of medical conditions which could impair functioning to the extent necessary to satisfy the statutory standard for liability. The regulations recognize this by providing for individualized assessment of the actual degree of functional impairment of adults whose medical findings do not entitle them to a presumption of disability by meeting or equaling the listing.

Zebley, at 73 (emphasis in original).

Finally, the Secretary argues that requiring individualized assessments for children would be time-comsuming (Brief for

the Petitioner, at 44 n. 25) and expensive (Petition for Writ of Certiorari, at 18). These claims do not save the regulatory scheme from constitutional infirmity. Though "fiscal integrity . . . is a legitimate concern of the State," Lyng, 108 S. Ct. at 1193, "[t]his does not mean that [government] can pursue the objective of saving money by discriminating against individuals or groups." Id.

In sum, the Secretary fails to demonstrate that the Regulations are rational or non-arbitrary. The scheme is, rather, inconsistent with and so attenuated to the purposes of the SSI program that the Regulations fail to provide equal protection.

B. The SSI Regulations Fail To Provide Due Process.

The Regulations preclude children from going beyond the Listings to obtain individualized assessments of their functional limitations. In doing so, the Regulations deny children an essential opportunity afforded adults through an RFC assessment to support their claims to SSI benefits by submitting all relevant information about their condition.

For adults, an RFC assessment is deemed by the Secretary to be "crucial if the person does not meet or equal the Listings." 50 Fed. Reg. 35042 (1985) (emphasis added). The scheme for adults thus furthers the statutory mandate to consider the "combined effect of all the individual's impairments," 42 U.S.C. §1382c(a)(3)(G) (Supp. 1989), and "all [the] evidence available" about the individual's disability. 42 U.S.C. §1382c(a)(3)(H) (Supp. 1989).

Disability benefits are "property" under the Fifth Amendment, Mathews v. Eldridge, 424 U.S. 319, 332 (1976), and due process protections should be available to persons already receiving public benefits as well as to those simply applying for eligibility. Walters v. National Association of Radiation Survivors, 473 U.S. 305, 320 n.8 (1984); see also Wright v. Califano, 587 F.2d 345, 354 (7th Cir. 1978) ("denials do not necessarily deserve less due process protection than terminations").

The due process guarantee of the Fifth Amendment forbids the government from depriving property from persons without affording those persons an opportunity to be heard "in a meaningful manner." Mathews v. Eldridge, 424 U.S. at 333. To be meaningful, "the hearing required by the Due Process Clause must be . . . 'appropriate to the nature of the case.' It is a proposition which hardly needs explication that a hearing which excludes consideration of an element essential to the decision . . . does not meet the standard." Bell v. Burson, 402 U.S. 535, 541-42 (1971). But the Regulations exclude from consideration of children for SSI eligibility any evidence of disability not specified in the Listings, irrespective of a child's actual level of functional impairment. Because the Listings are incomplete, this categorical exclusion of evidence probative of functional disability denies children a meaningful opportunity to be heard. The Regulations therefore deny due process to children.

In sum, both the Regulations and the SSI statute are constitutionally defective if the Regulations are found to be consistent with congressional intent. This Court can avoid these constitutional problems by finding the Regulations conflict with the mandate of Congress.

The SSI Regulatory Scheme Impacts on a Large Population of Similarly Vulnerable Children.

The United State Department of Health and Human Services (HHS) reported in 1986 that six percent of all live births (216,000 children) are admitted each year to neonatal intensive care units in the United States, and that 2.5 percent (90,000 children) annually are born with major disabilities, such as cleft lip, heart murmur, and "truly life-threatening conditions." Financial Support for Disabled Infants with Life Threatening Conditions: A Report to Congress, Executive Summary, Health and Human Services (Mar. 28, 1986).

Approximately 30 percent of all persons under age 18 are affected by chronic physical or mental impairments. New-

acheck, The Costs of Caring for Chronically Ill Children, 4 Business & Health 18 (1987). Almost 1 million children are limited in their ability to participate in minor activities, such as sports and recreational pursuits. Id at 19. Another 1 million children are more severely limited by chronic illness and are restricted in the kind or amount of their major activities such as school for school-age children and play for preschool-age children. Id. At the most severe end of the spectrum are children unable to engage in any major childhood activities. Nationwide, approximately 150,000 children, including about 100,000 residing in long-term care institutions, fall into this category. Id.

Thus, many infants and children today have physical and mental disabilities, often serious enough to be life-threatening. These children require continued medical, social, and emotional assistance as they grow and mature. This assistance not only would sustain life, but could — increasingly with medical advances — provide the means to rehabilitate these children to become productive adults.

The SSI regulatory scheme's impact on children with disabilities is better understood by example. Consider the realities facing children with Down Syndrome, Spina Bifida, Hemophilia and Cystic Fibrosis.

One infant in 1,000 is born with Down Syndrome, which translates into 4,000 to 6,000 births per year. Telephone interview with Diane Barounis, Resource Specialist for the National Down Syndrome Congress (July 18, 1989). These children are mentally disabled and often possess cardiac, musculo-skeletal, and gastrointestinal impairments. Repeated surgical procedures are often required to correct heart problems such as holes in the heart, incorrect circulation of blood, and heart murmurs and to repair club feet, dislocated hips, and other skeletal deformities.

The Center for Disease Control in Atlanta reports that 3000 children are born each year with Spina Bifida. Telephone inter-

view with Katherine Hartnett, Executive Director of the Spina Bifida Association of America (July 18, 1989). These children all encounter residual physical disabilities of varying degrees even after the spinal cord is surgically covered and reimplanted into the spinal column. Many children with Spina Bifida will be paralyzed in both legs, requiring the use of a wheelchair, walker, or braces. Nerve damage will create incontinence/retention of bladder and bowels, requiring colostomies and iliostomies for some children. Other children might require an indwelling tube (catheter) in their bladder or have to wear incontinence supplies, such as diapers.

Another problem associated with Spina Bifida is hydrocephalus, an abnormal collection of cerebrospinal fluid. Unless this condition is corrected by the placement of a tube in the brain (a shunt) to drain the excess fluid into the abdominal cavity, the head will enlarge and the child will suffer brain damage, including mental retardation. As the child grows, the shunt must be surgically replaced several times to allow for the increasing length of the neck and trunk. Shunts can also become plugged or infected, requiring further surgical intervention.

The Hemophilia Foundation reports that one in 4000 live male births results in a baby boy with the bleeding/coagulation disorder of Hemophilia. Chicago Tribune, Apr. 23, 1989, \$10 (Magazine), at 12. Children with Hemophilia have varying degrees of the coagulation impairment ranging from mild to severe. A family with a child with mild Hemophilia pays on average \$2000 per year for treatment, while treatment for a child more severely affected costs on average \$18,000 to \$36,000 per year. Telephone interview with Chris Barnard, Social Work Coordinator for Hemophilia of Indiana, Inc. (June 28, 1989).

Cystic Fibrosis is the most common genetic disease affecting children. Cystic Fibrosis Foundation, An Introduction to Cystic Fibrosis 2 (1987). Approximately one child in 2,000 live births will be born with Cystic Fibrosis. Id. Ten million Ameri-

cans (one in twenty) are symptomless carriers of the Cystic Fibrosis gene. Id.

Cystic Fibrosis is a fatal disease, with a median age of death at twenty-seven years of age. Telephone interview with Jo Ann Dorgan, Assistant Director of Clinical Research, Cystic Fibrosis Foundation (July 18, 1989). It causes an abnormal accumulation of thick, sticky mucus that clogs the lungs and pancreas, interfering with breathing and digestion. Despite special diets, including enzymatic medications, and respiratory treatments several times a day that disrupt the usual life of a child, 95 percent of the children and young adults with Cystic Fibrosis altimately die from respiratory complications. *Id*.

Children with disabilities constitute a large and increasing population of vulnerable persons. These children have many needs, and they often lack the means to meet those needs. The importance to society of providing children early health care cannot be overemphasized. Medical advances have made possible the inclusion of persons with disabilities into the mainstreams of society. Physical and mental disabilities no longer, practically speaking, should hinder a person from earning a living, practicing the arts or governing this nation. Yet, to participate when older, children with disabilities need early access to health care. Early treatment gives disabled children a needed head start to enter their adult years as productive members of society.

Indeed, the failure to assist young persons with disabilities is bad economics. The labor pool is shrinking as the current majority of the work force ages and more workers retire. According to Jay F. Rochlin, Executive Director of the President's Committee on Employment of People With Disabilities, "idlemographics has given us a 20-year window of opportunity to institutionalize employment of people with disabilities. During that period, employers will be desperate to find qualified employees." Quoted in As the Labor Pool Dwindles, Doors Open for the Disabled, N.Y. Times, June 22, 1989, at 1, col. 1. Paul G. Hearne, Executive Director of the National Council on

Disability, recently told a conference on the disabled and the economy, "What I see now is policy makers and power brokers moving to integrate the disabled into the mainstream, to promote their independence, to make them people who pay taxes." Id. Unless children with disabilities obtain necessary health services when young, they may find it difficult or impossible to enter the workforce when older. The opportunity to become workers and taxpayers may then pass those children by — not because the opportunities won't be there, but because the early rehabilitative care wasn't financially obtainable when the children needed it most.

Because disabled children are vulnerable to discriminatory nontreatment, and treatment could rehabilitate these children to become productive members of society, the Secretary should assist these children — at the very least in a constitutionally legitimate and impact-neutral fashion.

111. The SSI Regulatory Scheme Increases the Risk of Discriminatory Denial of Health Services, Including Life-Sustaining Care, to Similarly Vulnerable Children.

The Secretary's Petition for Writ of Certiorari argues that "[t]he issue in this case is of considerable practical importance" because, among other things, "additional benefits . . . may have to be paid when a new standard is applied" to children already denied benefits under the existing standards. Petition for Writ of Certiorari, p. 17. In addition, implementing new standards "could be even more cosily and time consuming." Id. at 18.

The import of this argument is not only constitutionally troublesome, but ethically appalling. For too long, persons with disabilities have encountered substandard care or received no care at all because of "costs." Children with disabilities often bear a double burden: the stigma of handicap and the inattention of those on whose care children must depend.

The ramifications of a restrictive SSI policy for children are

far-reaching and ominous. Discrimination against, even infanticide of children with disabilities is still pervasive, as the tragic history of the discriminatory, even lethal treatment accorded children with disabilities demonstrates: "Ancient [discriminatory] attitudes continue to have an impact on our notions of the value of disabled newborns [and children] and continue to play a role in their loss of life." Moseley, The History of Infanticide in Western Society, 1 Issues in Law & Med. 345, 361 (1986). Practices of and attitudes justifying discrimination against children with disabilities must be repudiated, not embraced.

Surveys of contemporary attitudes reflect a disturbing latent bias against children with disabilities, especially within the medical profession. "The data indicate that physicians generally have a pessimistic outlook about the life of a disabled newborn and generally acknowledge that there are circumstances in which nontreatment is justified. This is not the only attitude reflected in the surveys, but it is the dominant one." Turnbull, Incidence of Infanticide in America: Public and Professional Attitudes, 1 Issues in Law & Med. 363, 374 (1986). Physicians are significantly more pessimistic than psychologists, educators, allied health professionals, and social workers toward the prognosis for individuals who are, for example, mentally retarded. Id. at 376, citing Wolraich & Superstein, Assessing Professionals Prognostic Impressions of Mental Retardation, 21 Mental Retard. 8 (1983). Almost all groups in society, however, hold negative attitudes toward persons with disabilities. Richardson, "Reaction to Mental Subnormality," in The Mentally Retarded and Society: A Social Science Perspective 77 (M. Begab & S. Richardson, eds. 1975).

These negative attitudes may be the primary reason Down Syndrome children with leukemia are being refused bone marrow transplants, for example. A recent survey of bone marrow transplant centers in the United States found the number of Down Syndrome children receiving bone marrow transplants between 1979 and mid-1987 inexplicably low. Arenson & Forde,

Bone Marrow Transplantation for Acute Leukemia and Down Syndrome: Report of a Successful Case and Results of a National Survey, 114 J. Pediatrics 69, 72 (1989). According to Arenson and Forde, based on the reported incidence in the United States of acute lymphoblastic leukemia, 60 to 68 children with Down Syndrome could be expected during the 7 1/2 year period to have undergone bone marrow transplants. Yet the authors' survey of 58 transplant centers (96% of all centers treating children) indicated that only 16 Down Syndrome children in this period actually received transplants. Id.

The authors suggested the most likely reason for this gap was physician bias against Down Syndrome children:

The likelihood of parental refusal of bone marrow transplants is low unless the referring physician discourages the family. We cannot determine from available information why so few Down Syndrome children have undergone bone marrow transplants, but it seems reasonable to suspect that physician bias that Down Syndrome children are suboptimal candidates for bone marrow transplants has played a role. . . . Although Down Syndrome children may have an increased risk for acute pulmonary and infectious complications after bone marrow transplants, our survey suggests that Down Syndrome children who undergo bone marrow transplants have outcomes that do not differ significantly from those of normal children. We conclude that current experience does not justify denial of bone marrow transplants of acceptable candidates with Down Syndrome. In fact, denial of bone marrow transplants, based solely on the diagnosis of Down Syndrome (or any other handicap), ic in conflict with federal guidelines for the provision of medical care to handicapped children.

Arenson, at 72.

In an accompanying editorial, the Journal of Pediatrics reflected on the study's suggestion that leukemia treatment centers may be discriminating against Down Syndrome children solely because of mental disability. Though holding it would be "simplistic and erroneous to assume an overt prejudice against treating Down Syndrome children," the *Journal* was disturbed by the implications of what it deemed to be a more subtle, more potent form of bias:

Prejudice need not be conscious to be present. Unintended bias against Down Syndrome chidren can be all the more powerful for being unarticulated, especially among professionals who hold high ideals. . . . Very few individuals are expressly prejudiced against such patients, but many of us may be predisposed to believe the first evidence we read that Down Syndrome children will not do as well as others. Or we may be predisposed to overgeneralize data collected from one group of patients to cover all patients when the results fit our assumptions or are otherwise convenient. Moreover, bias can be institutional, as opposed to personal. . . . Perhaps what Arenson and Forde have discovered is not a malign profession or callous parents but an unintended and powerful bias embedded in institutional practices - a prejudice all the more powerful because it is unacknowledged and difficult to examine, being cloaked in high ideals and having a professional imprimatur.

Churchill, Bone Marrow Transplantation, Physician Bias, and Down Syndrome: Ethical Reflections, 114 J. Pediatrics 87-88 (1989).

The Journal concluded that "[a]ctive advocacy at all levels is . . . required because we do not start from a neutral position, but from one already tilted toward a social judgment of persons with Down Syndrome and other handicaps as somehow less deserving of our efforts." Churchill, at 88.

The practice of medical decision-making based on the economic resources of a child's family and the economic policies of government is also all too real. A disturbing example is the nontreatment program initiated in 1977 at the Oklahoma Children's Memorial Hospital (OCMH), and reported in an article by Gross, Cox, Tatyrek, Pollay & Barnes, Early Management and Decision Making for the Treatment of Myelomeningocele,

72 Pediatrics 450 (1983). The article, written by members of a team of medical personnel responsible for recommending non-treatment, evaluated the program between 1977 and 1982.

The team at OCMH developed a selection process for deciding when to treat infants born with myelomeningocele, a genetic but treatable malformation of the spine. The physicians employed nonmedical criteria, including the socio-economic status of an infant's family and even the fiscal policies of the federal government. This criteria was used to determine whether an otherwise routine regimen of surgery and care should be recommended or discouraged for each infant. Parents of infants given "pessimistic assessments" were advised they could refuse all necessary surgery.

The OCMH selection team relied on a "quality of life" formula — QL + NE x (H + S) — first published in Shaw, Defining the Quality of Life, 7 Hastings Center Report 15 (1977). "In the formula, QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family and S is the contribution from society." Gross, at 456.

If the team subjectively considered the child's parents to have sufficient wealth, then the team recommended vigorous treatment. If the team concluded the parents did not meet the team's financial criteria, they advised "supportive care only." Supportive care purportedly was intended to keep the infant "comfortable" until death occurred. Routine corrective surgery was withheld. If hydrocephalus were present, then the cerebrospinal fluid was not drained, causing gross enlargement of the infant's head. Antibiotics and sedation were not prescribed. *Id.* at 452.

Similarly, the team considered "contribution of society" to be relevant to the children's interest in treatment or nontreatment. That is, the team believed cuts in governmental programs for children in some circumstances could render life-saving treatment for children with disabilities inadvisable:

We feel that at the present time society is giving a schizophrenic message to the families of patients with defective newborns Groups supporting sanctity of life are insisting that all such babies be saved, and the federal government has recently adopted this stance by threatening the withholding of funds from hospitals in which such babies might be allowed to die. Parents are also informed that under Public Law 94-142, children have a right to an appropriate education tailored to individual needs. On the other hand, support for funding to finance medical needs is diminishing with attempts to cut government spending, and schools are struggling to provide the increased personnel necessary to comply with PL 94-142 as their budgets tighten. It is becoming easier to visualize a cruel irony in which maximum treatment would be mandated for newborns with myelomeningocele, but funding for their nurture later in childhood is unavailable. This would, in effect, be a delayed triage with no criteria except the availability of financing.

Gross, at 456.

The team asserted that "there is no evading the fact that external circumstances are crucially important in the outlook for the newborn with myelomeningocele. Thus, the treatment for babies with identical 'selection criteria' [i.e. medical indications favoring treatment] could be quite different, depending on the contribution from home and society." Id.

Indeed, the team proudly reported that "all 24 babies who continued to receive only supportive care [i.e., nontreatment] . . . died. These babies did not receive active treatment for infection and other acute illnesses." *Id.* at 453. But three of the five children recommended for supportive care and yet treated at their parents' insistence survived. *Id.* at 452.

A difference between the infants at OCMH recommended for treatment and those recommended for nontreatment often only was the economic status of the child's family. See Sherwood, Take Two: Who Lives, Who Dies? — Part II, Cable News Network Documentary, Radio-TV Monitoring Service, Inc.,

Transcript at 2 (February 22, 1984).

Systematic nontreatment of poor and disabled children such as reported at OCMH will only spread if the pool of children wrongly denied SSI benefits increases. The Secretary's capricious policies may become yet another "external circumstance" influencing physicians to make for disabled children what should be purely medical decisions.

The Secretary's policies may additionally influence parental attitudes to the children's detriment. Upon the birth of a child with disabilities, parents experience a range of emotions, both negative and positive. Evans, The Psychological Impact of Disability and Illness on Medical Treatment Decision-Making, paper delivered to conference sponsored by National Legal Center for the Medically Dependent & Disabled, Inc., on "Current Controversies in the Right to Live, the Right to Die; Legal, Medical and Ethical Issues," Washington, D.C., April 13, 1989. Financial worries are inevitably included in the mix of parental concerns. Maintaining a policy of strict medical eligibility, where adults are deemed eligible for SSI and therefore perhaps for Medicaid, while children with equal or greater functional impairments are nevertheless denied coverage, may impose a bewildering emotional burden on indigent parents. A repulsive option might then allure: consent to nontreatment not because treatment may be futile, but because ordinary and effective treatment is beyond the parents' financial reach.

Your amici thus fear that if the Secretary continues to deny SSI benefits to children disabled functionally, those children and others similarly situated will encounter an increased risk of denial of treatment based on non-medical, economic assessments by the medical profession in particular and society in general.

CONCLUSION

The Secretary's SSI eligibility process for children is constitutionally defective and detrimental to the interests of children with disabilities. For these reasons, your amici support the claims of Brian Zebley, Joseph Love, Jr., Evelyn Raushi, and the class of children they represent.

Respectfully submitted,

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